



Intellectual & Developmental Disabilities Task Force

MEETING MINUTES

The Intellectual & Developmental Disabilities Task Force met on Tuesday, December 19, 2017 at 11:00 a.m. (EST), at Ivy Tech Community College, Shreve Hall 200 Daniels Way, Bloomington, Indiana 47404.

Task Force Members present: Joseph Langerak, Jason Meyer, Kathleen McAllen, Kim Milas, Betty Williams, Kim Dodson, Lt. Governor Susanne Crouch, Kylee Hope, Julie Reynolds, Jonathan Burlison, Christine Dahlberg, Steve Cook and Kevin Moore

Also present: Rebecca Kasper and Derek Nord

Absent: Dr. Pam Wright (Dana Long attended in her place), Allison Taylor (Kelly Flynn attended in her place), Judge Mary Beth Bonaventura (David Reed attended in her place), Trent Fox (Aaron Atwell attended in his place) Debbie Pierson

- I. **Lt. Governor Suzanne Crouch calls meeting to order (10:00 a.m.)**
 - a. **Introduction of Task Force Members**
- II. **Listening Session – Facilitated by Leslie Green, CEO, Stone Belt (11:05 a.m. – 11:55 a.m.)**

Kathy McNulty – Introduced SIPN (Strategic Indiana Provider Network) as a statewide resource.

Douglas Beebe – Benchmark, President and CEO. *Spoke about waiver and Supervised Group Living Homes. Waiver services have become the preferred service. This is trending and leaves a hole because people with ID/DD and may be why nursing homes are being utilized.*

Jim Wiltz – Stonebelt, Director of Clinical Services – INARF *invited him to discuss dual diagnosis. In 2017 NADD conducted a study nationwide where 1.3 billion only \$145 million is spent. Today we have a lack of resources to provide services for this population. U of NW – state of IN paid for study – mental health services are only available to a small percentage. Clients with the most mental challenges have the highest costs. Crisis services don't exist and they are needed.*

Bitta DeWeiss – Stonebelt, Director of Service Development. *Employment for people with disabilities - 17.9 percent are working. Suggests fully implementing Employment First and then focus on short term and long term solutions. Simplify VR so focus can be on individual. Long term supports need funding.*

Rhonda Duzan – Individual with a disability. *Works at Ivy Tech four days a week in the kitchen. At Stonebelt she also works. She enjoys working and is married – they enjoy doing things in the community like everyone else likes to do. Rhonda has friends at her work.*

Dan Stewart – Achieva Resources. *Bringing a concern to the Chairman regarding the VR Commission. He has been chair for two terms. All positions were terminated in June, 2017. Members had to resubmit applications and he's concerned that the Bureau of Rehabilitation Services Director has no support. The State VR Commission is out of compliance and this could have a negative impact on RSA funding. Dan recommends that a new commission be appointed as soon as possible. There are critical issues that*



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need addressed. He provided a letter. The Lt. Governor responded that before the end of the day this will be addressed.

Michael Ely – Individual with a disability. *He would like to see an increase in wages for direct support professionals – Medicaid pays for all his staff and provide his personal care – grooming, etc. They help shopping and without a DSP he could not do anything by himself. They play a big part of his life. Risk Mgmt., medicine, career counseling and transportation...long list of activities.. References the low wage of DSPs but not enough to make a living.*

Sharon Hauss – Parent of three children. *(Michael who made previous public comment is her son). Her son Michael has been on a waiver for the past 16 years – Mom was primary and sometimes the only caregiver for 30 years. Michael’s disability affects all of his physical disabilities. Today, she’s speaking on behalf of aging caregivers and how persons with disabilities are put on the CIH waiver when the primary caregiver’s health is declining. Now must be 80+ years, in nursing home or if the primary caregiver dies. How can the state put an age on when the primary caregiver can no longer.... The time to speak expired. She was then able to continue speaking: She had a health crisis and doctor recommended that she place her son in a nursing home. Another time, she had her knees replaced and had a lifting restriction but was not allowed to get increased hours for help in the home for her son. We can’t afford to wait until the primary caregiver’s health declines so much that they can’t care for an individual. Please reconsider the “specific” age that is required. Other caregivers have shared that they couldn’t die – fearing no one could care for their dependents. Wavier budgets need to be increased so that we can do the best job possible for their dependents.*

Anne Higley – Mother of two young adults with Autism. *One child is a student at Ivy Tech and the other is a student at IU. No services but some here and there with VR and other they pull together. 1634 Issue – 23 years old son who wants a job – eligibility is based on income but he’s not eligible for the waiver. Access is now blocked because we’re a 1634 state. We are linked as a state to the federal eligibility process. Hundreds of families are in a hamster wheel of appeals. The problem is that SSA is making decisions about eligibility determinations. As a result – her son is not likely to have supports until he is 26 years old. Please look into this.*

Jason Harris – Individual with a disability. *With the Medicaid cut backs, he’s afraid that staff will not be there and needs will not be met. He’s a client of Stonebelt. Some needs are greater than others *needs two staff. Some clients in SLP need more help for staff safety and for the clients.*

Task Force Member Christine Dahlberg *asks for clarification on 1634 from comment maker*

Anne Higley: *Administrative rule in 2014 with the purpose to align state eligibility with SSI eligibility income thresholds. It made it to where people who were already receiving Medicaid supports as children as age 18 they only had to submit one application. The*



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fallout is that in cases of redetermination is that families file application for SSI and they are denied and then DFR is denying them on SSI determination. Services and supports are pulled out from individual.

Even though her son was targeted – wavier supports don't consider income as a child and as he is a young adult at 18 it should be determined on his income along (commented Christine) There are seven other states that have different criteria to determining eligibility...

Joe Langerak asked what the appeals process is like. Reply is that it is byzantine and protracted. Initially applied for Medicaid when son graduated from high school. He was denied based on his 529 plan held in his father's name. Told they could re-apply. Now he's in post-secondary-ed. Because of ABLE Act, he can save \$\$\$. He wants supports so that the can get a job. Denied now because they believe that he can work. Working and sustaining work requires short and long term supports that come from a Medicaid waiver.

Another SSI appeal – before they can access Medicaid. Waiting for a face to face hearing – that process is so backlogged – 18 months to 2 years before they will even hear his case. Steve Cook asks how long the original determination/denial of eligibility took. The answer is four weeks.

New Comment (no name provided) – *Working with brain injury CIH waivers. Providers are having difficulty to get staff that the waiver covers because the reimbursement rates are so low. Someone could have a waiver and still not have the coverage that they need to live safely in the home. Great to have the wavier but it doesn't help if we don't have the staff to cover.*

Ella Boyd – Executive Director of the Arc of Bartholomew County. *Ella is a family member of an individual with a disability. Waiver amount is not enough. Her brother's guardian is 91 years old.*

Laurie – Speech language pathologist – *Laurie used to work on teams. Rules under Mitch Daniels limited care teams. Since 1992, there have been two rate increases. It isn't increasing like private practice is. Parents are often calling asking her to provide her services because there aren't enough pathologists to provide services. Maybe think about OT and PT to see about restating services. More dollars are dedicated to behavior consulting and yet no therapists to provide services.*

Ann Higley – *additional comment. Both her children, a son and daughter, are pursuing degrees. Her daughter was diagnosed later in life. She would like to look into VR providing more supports to individuals in post-secondary education. An occupational therapist for her daughter addresses her time management and fears and phobias – it has been an amazing experience. Provider based supports for post-secondary bound students. Specialized supports at the provider level could help.*

Jason Harris additional comment – *With staffing being so short in the group homes it is a safety hazard. We hope that we can do better to provide staff with a living wage. He hopes that Medicaid doesn't get cut because that is the source of medical care.*



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Psychiatrists need to treat/help – we need more because now many get a Nurse Practitioner. We need more behaviorialists.

Jim Wiltz – *Additional comment. Wanted to point out that the Self Advocates are emphasizing the shortage of staff. Shared his experience in an institution. They aren't even paid \$11/hr.*

III. Review and Approval of Minutes from November 20, 2017 Meeting

There was a motion to approve minutes and a second motion to approve. The minutes were approved.

IV. Review and Discuss Draft Task Force Vision and Values

a. Prepared by Derek Nord, based on first meeting

Kylee Hope read the Vision stating that it was a draft. Task Force Members gave input and discussed various terms used.

Lt. Governor Crouch wants to ensure that whatever is agreed upon that it must be measured.

Derek Nord asked for clarification on “live work and play” comment and ensuring that the multidimensional aspects of life are covered.

V. Current Environment and Impacts on Services (from Task Force Member's Perspectives)

a. Based on your experiences, and looking ahead, describe the greatest need or biggest challenge impacting supports and services to individuals with IDD and their families over the next ten years.

The suggestions included: Support services for living at home; providing a living wage for caregivers and support staff; better training for caregivers and support staff; a refocus on supports outside of paid supports is needed; high expectations from day one in early intervention all the way to school and then into the workforce; options for optimum health like attending gym classes.

Kylee Hope reminded everyone that this is a 10-year plan and hears the desire for self-direction. There are a lot of complex needs and there needs to be a system designed and flexible enough to respond to what the public and family members want.

b. How would you recommend responding to this need or challenge over the next ten years? (If applicable, identify an associated law, regulation, policy or funding source.)

The suggestions included: Better pay and developing a career ladder – example of entry level to PhD career path of person who made public comment.

Lt. Governor Crouch asked if technology is being utilized. Jon Burlison mentioned tele-psychiatry, telemedicine can be used in rural areas.

Joe Langerak suggests that with the deployment of services and early intervention there is a return on investment – and less services are needed as an individual gets older. First Steps changed his family's lives and suggests that it



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is a great program to build upon. Steve Cook stated that First Steps has lost more than half of its providers and there are counties where they can't find coverage.

Jon Burlison mentions diversified ABA therapy needs to be explored because that provided initial impact to families – especially to children with autism.

c. Identify two additional needs or challenges impacting supports and services over the next ten years.

Lt. Governor Crouch suggests that position papers from Task Force members be submitted or sent in and the agenda can be based upon this.

Additional needs mentioned, include: The uncertainty of federal and state laws, the impact of the opioid crisis, affordable housing for low income, transportation, individuals with a dual diagnosis, the workforce issue, technology and best practices to turn into reimbursement models.

The Lt. Governor noted that in rural areas across the state that services are limited.

VI. Impact of Home and Community Based Services (HCBS) Settings Rule

(DDRS Director Kylee Hope)

Kylee Hope presented an overview of the Impact of Home and Community Based Services Settings Rule. The purpose of the regulations are to ensure members receiving HCBS have full access to the community.

Status of plan: Division of Aging, DMHA and DDRS has received initial approval and are waiting for final approval. This Task Force will help define services that have an emphasis on developing supports that are person centered.

Key concepts for participation in the community. Federally we are required to move in this direction. All services as we know are interwoven. Yes, we must evolve services to be compliant but we have an opportunity to have better choices for an individual.

Julie Reynolds mentioned community Integration is not taking someone to the mall. How do we embrace community? Often the community isn't ready for the people that we support. We haven't done a good job of "meeting our neighbors"- Staff needs to be trained to know where to go.

Since 1997, in early intervention, the families are served in the natural environment where children and family spend their time. The Rule is saying what is already occurring. Adults are behind 20 years what the early intervention is doing right now.

Lt. Governor Crouch asks Kim Dodson and Steve Cook to comment on what they see in Washington, DC. Day to day there are changes and uncertainty. Rumors of rescinding the settings rule are there.



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VII. Data Work Group Update (Lt. Governor's CFO, Lisa Acobert)

a. Purpose

The Goal of the work group is to ensure that the report is in compliance with the statute and to supplement the group of the Task Force. The Data group will meet early in January. INARF, The ARC of Indiana and FSSA are represented on the workgroup.

b. Data required to meet statutory requirements of HEA 1102.

c. Average increases/decreases in budgets for IDD services over the past ten years.

d. Specific Data Needed by Task Force Members for Meeting #3

- i. Meeting #3 Agenda Topics – Current System: Population Served and
 - 1. Current Data on Population Served (including Early Intervention)
 - 2. What are the entry points to BDDS services?
 - 3. Feedback on Service and Support Needs
 - 4. What do people get and what do they need?
 - 5. Scope of Services
 - 6. Crisis Needs

VIII. Additional Agenda Items – Meeting #3 or remainder of Task Force Agenda

IX. Next Meeting - **Friday, February 23, 2018 10:00 a.m. CT**
Boonville Warrick County Public Library
611 West Main Street
Boonville, IN 47601

X. Meeting adjourned